

## The impact of educating parents of leukaemic children on the healthy siblings' quality of life

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### Abstract

**Objective:** To study the effect of educational programme for the parents on the quality of life of healthy siblings of children with leukaemia.

**Methods:** The quasi-experimental study was conducted from January to July 2006 at the Oncology Ward of Shahid Faghihi Hospital, Shiraz University of Medical Sciences, Iran. It involved two groups of siblings of children with leukaemia. Parents of the children participated in 3 educational sessions and the quality of life of their healthy children was surveyed before and after education. The data was collected through a questionnaire developed by the Netherlands Organisation for Applied Scientific Research Academic Medical Centre (TN0-AZ1) which has been specially designed for children aged 7-15 years. In this study, the parent form of the questionnaire, including 7 dimensions, was used. Sampling was done by convenient purposive method. The collected data were analysed using SPSS 11.5.

**Results:** The differences in the quality of life scores of the experimental and control groups before and after education was  $-28.8 \pm 11.3$  and  $3.6 \pm 4.5$ , respectively. Also by regarding the mean difference of the two groups, the independent t-test showed significant difference before and after the education ( $p < 0.01$ ). There was a significant difference between the two groups on all dimensions ( $p < 0.01$ ) in such a way that the educational interventions was able to improve the quality of life in terms of physical complaints, autonomy, social, cognitive and motor functioning, positive and negative emotions.

**Conclusion:** The educational programme was effective in improving the quality of life and its dimensions among healthy siblings of children with leukaemia.

**Keywords:** Educational programme, Quality of life, Siblings, Leukaemia. (JPMA 63: 249; 2013)

### Introduction

Chronic diseases are often disabling due to their progressive process and are followed by complications such as fatigue and social seclusion which reduce the power of individual, family and society.<sup>1</sup>

Among chronic diseases, cancer is one of the disorders which have always attracted the attention of researchers. This disease is reported to be the second cause of mortality among children aged 1-14 years and its prevalence in this age group is approximately 129 in one million.<sup>2</sup> Acute lymphoblastic leukaemia (ALL) is the most common childhood malignancy.<sup>3</sup>

Cancer diagnosis in children can be considered a crisis for the family, causing loss of their time and energy and usually resulting in decrease of the ability of parents to look after the requirements of their healthy children.<sup>2</sup>

Healthy children of such families may suffer from this disorder in social communications due to lack of attention,

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miscommunication with parents, relatives and friends, and also, due to limitations in recreation, playing and amusement, the child becomes secluded and makes less relation with friends and even with parents.<sup>4</sup> On the other hand, these children are faced with fear, anxiety, inconvenience, despair, nervousness and a feeling of guilt.<sup>5</sup>

The siblings of children with leukaemia during this crisis will be involved with several physical problems especially drowsiness, fatigue, gastrointestinal problems, etc.<sup>6</sup> which may negatively affect the body and motor functioning of the healthy children. The problems to which the siblings of children with leukaemia are faced result in declining their quality of life (QOL) as to physical, motor, social and cognitive functioning, and positive and negative emotions.<sup>7</sup> Moreover, some other researchers have reported defects in psychological, familial and social dimensions of QOL of such children.<sup>5</sup>

Implementation of the educational programme in one study led to improvement of the parents' awareness about children with beta-thalassaemia major disorder.<sup>8</sup> Researchers believe that performance of some interventions, especially educational programmes for parents and healthy siblings of the children with chronic

disease, is effective in increasing the knowledge and adaptation of these children and reduces their behavioural problems.<sup>9,10</sup> Performance of those interventions leads to promotion of psychological health and coping of healthy siblings of children with cancer and finally improvement of their QOL. In addition, some investigators have indicated that implementing educational and supporting programmes lead to the reduction of anxiety,<sup>11</sup> distress,<sup>12</sup> behavioral problems<sup>13</sup> and promotion of social competency of the healthy siblings of a leukaemic child.<sup>12</sup> Other researchers have stated that performance of interventional programmes in an educational camp for healthy siblings and parents having a child with cancer will lead to improvement of QOL of healthy siblings in physical and psychosocial aspects.<sup>14</sup>

Considering the fact that there are few researches on the effect of interventional programmes on the QOL of the family of children with cancer in Iran, this study was conducted to survey the effect of an educational programme for the parents on the QOL of healthy siblings of children with leukaemia.

### **Subjects and Methods**

The quasi-experimental research was carried out on two groups of subjects (experimental and control) from January to July 2006.

The study population included 7-15-year-old healthy siblings of children with ALL who had been referred to the Oncology ward of Shahid Faghihi Hospital of Shiraz University of Medical Sciences, Iran.

The inclusion criterion was: only one child with cancer in the family and no other chronic diseases or cancer in the other members; minimum one month and maximum one year since the diagnosis of leukaemia in the child by a specialist; patients should not have another recognised chronic disease except ALL; siblings of the sick child should be healthy; the age range of the healthy siblings should be 7-15-year-old; and the sick child should be from the nuclear family consisting of father, mother and children and no other relatives (e.g. grandparents).

The sample size of the study with a power of 80% ( $\alpha = 5\%$ ) was determined to be 26 individuals in the experimental and control groups. By considering the possibility of attrition in the study (around 20%), this number was increased to 33 individuals per group for a total sample size of 66. Sampling was done by convenient purposive method in such a way that the researcher attended the study environment on different days of the week and allotted a number to patients who passed the inclusion criteria. Then they were divided into two groups using a

random number allocation.

After obtaining ethical approval from the hospital administration and informed consent from the parents, the pretest was handed out to parents in both the groups. The educational programme was then conducted for the experimental group. The programme consisted of 3 sessions of classes lasting 45-60 minutes each over a period of one week, and involved lectures, group discussion and question-and-answer sessions with parents in groups of 3 individuals. Leukaemia and therapeutic methods, the effects or problems resulting from cancer disease on the family and its coping strategies, the resultant effects or problems arising from the child's disease on various aspects of QOL of the healthy siblings and the application of problem-solving methods in order to reduce the problems and promotion of their QOL were the subjects of the first, second and third educational sessions, respectively. Thereafter, considering the need of each individual, the education and consultation was continued individually for a period of 3 weeks and the aforesaid points were repeated and the parents were given consultation. Two months later, i.e. 3 months after the beginning of primary education, a post-test was taken from parents of both the groups.

The data collection tool was a QOL questionnaire specially designed for children aged 7-15 (parents form) by the Netherlands Organisation for Applied Scientific Research Academic Medical Centre (TN0-AZ1). This questionnaire was prepared in 1998 and has to be completed by the parents. It has 7 functional sub-scales, including physical (or body) complaints, autonomy functioning, social, cognitive and motor functioning, positive and negative emotions in 8 sub-groups.<sup>14,15</sup>

The participants responded to each item using a 5-point Likert-type scale with end points of 'always'/'never'. For the dimension of positive emotions, choosing 'always' scored 5 and choosing 'never' scored 1, and for other dimensions 'always' scored 1 and 'never' scored 5. The maximum and minimum scores in each dimension of QOL were 8 to 40. The possible range for the final score was 56 to 280. Higher scores indicated greater perceived QOL.

Content validity of this questionnaire has been confirmed by studies conducted in Germany<sup>16</sup> and Iran.<sup>17</sup> Statistical analyses were performed using SPSS version 11.5. Chi-square and t tests were used to compare the distribution of demographic characteristics of subjects in the two groups. Also, t-test was used to compare the QOL scores before and after training in experimental and control groups. A value of  $p < 0.05$  was considered significant.

## Results

Of the 66 subjects, 6 (9.09%) had to be dropped out either for not attending the educational sessions or for not adequately filling up the post-test questionnaire. The final sample size, as such, was 60, with 30 subjects each in the two groups. Among them 15 (50%) and 17 (56.7%) of the siblings of children with leukaemia were girls in the experimental and control groups, respectively. Most of the children with leukaemia in both experimental and control groups (n=18; 60.0% and n=20; 66.7% respectively) were boys.

The mean age of the sick children in the experimental and control groups was  $6.8 \pm 3.1$  and  $6.1 \pm 2.9$  years, and that of their healthy siblings was  $9.8 \pm 1.6$  and  $9.3 \pm 1.4$  years,

motor functioning dimensions. Another study also noted that holding interventional programme for cancer children and their parents caused the improvement of QOL dimensions (physical, emotional, social and school's functioning) of the siblings of cancer children.<sup>10</sup>

The current study also indicates that educational programmes for the parents improved the QOL of healthy siblings of children with leukaemia in the dimensions of cognitive aspect and positive and negative emotions. A study stated that the parents of children with cancer reported a high level of anxiety and depression (negative psychical dimension) among the healthy siblings of their sick children and that carrying out educational sessions reduced such signs and symptoms significantly.<sup>11</sup> Other

Table 1 - Comparison of change of quality of life scores before and 2 months after intervention in the two study groups.

Groups	Experiment (30)	Control (30)	Standard error	P
Dimensions of quality of life	Mean difference $\pm$ SD	Mean difference $\pm$ SD	of differences	
Physical (body)complaints	-2/1 $\pm$ 1.5	-1 $\pm$ 1.6	0.4	0.008
Autonomy (auto) functioning	-0.8 $\pm$ 0.9	0.2 $\pm$ 0.7	0.2	0.001
Social functioning	-3.5 $\pm$ 2.7	-1.2 $\pm$ 1.7	0.6	0.001
Cognitive functioning	-1.7 $\pm$ 1.4	-0.2 $\pm$ 1.2	0.3	0.001
Motor functioning	-0.7 $\pm$ 0.7	0.3 $\pm$ 0.7	0.2	0.001
Positive emotions	-10.8 $\pm$ 3.8	-0.7 $\pm$ 1.9	0.8	0.001
Negative emotions	-9 $\pm$ 3.7	-0.9 $\pm$ 1.5	0.7	0.001
Total score	-28.8 $\pm$ 11.3	-3.6 $\pm$ 4.5	2.2	0.001

respectively. There was no significant difference between the experimental and control groups according to the mean age of the sick children and the age of their healthy siblings ( $p > 0.05$ ). Also, the mean number of family members did not show a significant difference ( $5 \pm 1.5$  vs.  $5.4 \pm 1.2$ ;  $p = 0.3$ ).

The difference between the QOL in experimental group before and after the intervention was  $-28.8 \pm 11.3$ , and in the control group it was  $-3.6 \pm 4.5$  ( $p < 0.01$ ) (Table).

## Discussion

The study suggests that the educational intervention for the parents was effective in the improvement of general QOL and all its dimensions among the healthy siblings of leukaemic children. The findings are consistent with those of another study.<sup>18</sup>

The siblings of children with cancer are faced with several physical problems, specially drowsiness, fatigue, gastrointestinal disorders, etc.<sup>6</sup> The crisis may affect some dimensions of the QOL of the healthy children negatively.<sup>7</sup> In this study, implementing educational intervention for their parents resulted in the improvement of the QOL in physical complaints and

researchers also indicated that interventional programmes in the form of a peer support camp for the healthy siblings of a child with cancer will lead to decrease in their distress.<sup>12</sup>

Furthermore, a study reported that implementing a psychological supporting intervention is effective in reducing stress and anxiety and increase of self-esteem of paediatric cancer patients' siblings.<sup>19</sup>

Our study shows that implementing the educational programme was effective in improving the autonomy (auto) and social functioning dimensions of QOL of the healthy siblings of the leukaemic children. A study performing peer support camp for healthy siblings of children with cancer stated that their social competence increased significantly.<sup>12</sup> Researchers believe that healthy siblings of children with leukaemia face many problems in QOL dimensions, especially in social functioning, that results in the decline in their QOL.<sup>7</sup> But interventional programmes for parents and healthy siblings positively impact coping and knowledge, playing an important role in relaxation of the family, prevention or reduction of psycho-social complications,<sup>2,8,10,12</sup> and improvement of

QOL among children.<sup>18</sup>

Intelligence quotient (IQ), ability of learning and the parent's interest have an effect on their learning rate and also on the outcome of education. To control these variables the samples were placed in two experimental and control groups randomly. The possibility of exchanging information between the parents of the experimental and control groups due to the same research environments was limitation of the current study.

## Conclusion

The study highlights the necessity of programmed education regarding the QOL improvement of healthy siblings of children suffering from leukaemia. It is necessary for healthcare team members specially nurses who are in charge of the important duty of supporting such families, to provide the required education to these families in order to improve their QOL, and to prevent the occurrence of problems among healthy children.

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